

### TERMS OF REFERENCE

#### BACKGROUND TO THE BETTER TREATMENTS 4 KIDS WORKING GROUP

A one-day Paediatric Research Roundtable was hosted by the NSW Government's Office for Science and Medical Research (OSMR) and the Children's Hospital, Westmead in December 2008. The Roundtable was attended by more than 30 clinicians and researchers from the three tertiary children's hospitals, the neonatal centres, NSW clinical trials centres, pharmaceutical industry and government agencies relevant to the health and well being of children and young people.

The purpose of the Roundtable was to explore the level of interest of NSW researchers from a range of disciplines in the potential formation of a NSW paediatric research network. Participants agreed that there were many potential benefits from the formation of a network and OSMR agreed to convene a Better Treatments 4 Kids (BT4K) Research Network Working Group to develop a sustainable model for the establishment of the paediatric research network.

It is proposed that the overall goal for the NSW BT4K Network will be facilitating research that leads to the translation of findings into improved practice for the use of paediatric treatments across the spectrum of age ranges.

The age range defined by the *European Agency Guidelines on Clinical Investigation of Medicinal Products in the Paediatric Population* will be adopted by the NSW Paediatric Research Working Group. Ages are defined in completed days, months, or years as follows:

- Preterm newborn infants (born <37 completed weeks gestation)
- Term newborn infants (0 to 27 days)
- Infants and toddlers (28 days to 23 months)
- Children (2 to 11 years)
- Adolescents (12 to 16 years)

One of the outcomes from the BT4K Working Group will be the development of a draft strategic framework for the research network including the governance structure for consultation with the potential membership.

## BETTER TREATMENTS 4 KIDS WORKING GROUP OBJECTIVES

The main objectives for the BT4K Working Group will be to develop a proposal that will ensure that the formation of a paediatric research network is founded on a strategic framework aimed at achieving:

- **Equity** – by ensuring the network structure has the appropriate membership that represents the 3 Tertiary hospitals, 9 Neonatal centres, the community health sector and caregivers.
- **Supervision** – by identifying an appropriate organisation to act as the host for the network coordinator, providing the necessary infrastructure and support for the position.
- **Networking** – through the provision of organisational support for membership in acknowledgement that membership takes time and resources.

If the goal of the network is to establish common infrastructure and shared resources, and priority setting, the necessary mechanisms to ensure that the network captures and is responsive to clinicians, researchers, trials centres, areas of expertise, consumer / advocacy groups, Aboriginal health research, industry professional bodies will need to be articulated.

The appointment of a network convenor will be a critical first step in establishing the research network. The working group will be tasked with scoping the proposal for the potential appointment of an OSMR-funded project officer to establish a Network, including the position description and priorities.

## MODUS OPERANDI

The BT4K Working Group is likely to meet 3-4 times over the first six to nine months of 2009.

It is envisaged that the BT4K Working Group will involve others as relevant to specific themes or strategies, and may co-op others to join sub-groups as necessary. The Chair of the BT4K Working Group may co-opt others to provide advice or form working parties for limited terms on specific issues which require a range of perspectives or input of particular expertise.

## LINKAGES AND REPORTING

The BT4K Working Group will maintain linkages with the broader NSW paediatric research sector by:

- posting the BT4K Working Group TOR and other relevant information on a secure section OSMR website ([www.osmr.nsw.gov](http://www.osmr.nsw.gov));
- maintaining liaison on a regular basis with the broader paediatric research sector;
- hosting a Consultation Forum to provide an opportunity for the paediatric research sector to comment on the draft Strategic Framework for the establishment of a paediatric research network.

## BETTER TREATMENTS 4 KIDS WORKING GROUP MEMBERSHIP

### Chair

Ms Suzanne Pope	Principal Policy Officer Office for Science & Medical Research
<b>NSW Clinical Trials Business Development Centre</b>	
Dr Catherine Bourgeois	Director, NSW Clinical Trials Business Development Centre
<b>Children's Hospital Westmead</b>	
Professor Jonathan Craig	Sub-dean, Clinical Epidemiology, The University of Sydney Westmead Children's Hospital
<b>Sydney Children's Hospital</b>	
Professor Glenn Marshall	Director, Centre for Children's Cancers & Blood Disorders
<b>Hunter Medical Research Institute</b>	
Professor Alison Jones	Professor of Pharmacology Chair Quality Use of Medicines Committee
<b>Sydney Neonatology</b>	
A/ Professor Nick Evans	Head, Department of Neonatology Royal Prince Alfred Hospital
<b>NHMRC Clinical Trials Centre</b>	
Professor John Simes (or representative)	Director, NHMRC Clinical Trials Centre
<b>Secretariat</b>	
Jean Hsu	Assistant Policy Officer, Medical Research Team

### SECRETARIAT SUPPORT

OSMR will provide secretariat support for the BT4K Working Group including the organisation of the meetings and the preparation of the final *Paediatric Research Network Strategic Framework*. Day-to-day management will be provided by Suzanne Pope, Principal Policy Officer from the Medical Research Team.

#### Contact Details:

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